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# Communication Between Huntington's Disease Patients, Their Support Persons and the Dental Hygienist Using Talking Mats

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## 1. Introduction

Communication is at the heart of any health care situation and individuals, who have difficulties describing their problems and expressing their needs, are in danger of being misunderstood or mistreated (Bartlett et al., 2008). Persons with Huntington's Disease (HD) have cognitive, emotional and motor problems which affect their communication and they frequently need support to be able to communicate in their daily life in general and in health care situations in particular. This chapter describes an effort to enhance communicative effectiveness in a dental and oral health care situation using Talking Mats. Eleven individuals, their support persons and a dental hygienist volunteered to help in exploring the use of this method in a clinical situation.

## 2. Background

Several of the changes associated with the progression of HD affect communication. Cognitive and emotional changes lead to fewer communicative initiatives, word finding difficulties, grammatical errors and difficulties in keeping track of what is being said in a conversation (Jensen et al., 2006; Yorkston et al., 2004). Furthermore, difficulties in managing complex discourse, tasks that involve interpretation of ambiguous, figurative and inferential meaning, are common and can appear early in disease progression (Chenery et al., 2002; Saldert et al., 2010; Saldert & Hartelius, 2011). Changes in motor function affect speech and articulation and symptoms of dysarthria are common (Hartelius et al., 2003; Yorkston, et al., 2004). The most frequently occurring perceptual deviations found in continuous speech in the study by Hartelius, et al., were mainly related to speech timing and phonation and reflected the underlying excessive and involuntary movement pattern. Deviation related to speech timing were variations in speech rate, shortened phrase length, and prolongation of interword and intersyllable intervals. Phonation-related aspects included increased pitch,

harsh and strained-strangled phonation, and decreased pitch variation. Imprecise consonant articulation was also prominent, but to a less severe degree (Hartelius et al., 2003).

Individuals with HD report that communication demands more concentration and is more tiring than before they had the disease (Hartelius et al., 2010). In the same interview study, family members and carers reported that the persons with HD had increased difficulties understanding complex information and that their personality changes also had led to decreased quality of communication with lack of in-depth talk, difficulties shifting focus in conversation, etc. One action to take to meet the communicative difficulties is to introduce different kinds of augmentative and alternative communication (AAC) strategies and tools. It is important that AAC, and communication aids in particular, are introduced early in the disease process, that they are simple to use and that a conversation partner is actively present to create structure and support in the use of the aid in real-life communication (Yorkston et al., 2004). Attitudes, skills and knowledge in conversation partners influence communication (Allwood, 2000; Kagan et al., 2004) and AAC-interventions relating to persons with HD should take the experiences of conversation partners into consideration (cf. Saldert et al., 2010).

Huntington's Disease is, in every sense of the word, a family disease, and significant others are often closely involved in care and communication surrounding the afflicted family member. The disease eventually leads to increasing need of health care and a multitude of health care contacts (McGarva, 2001; Roos, 2010). One of the health care professionals frequently in contact with persons with HD is the dental hygienist. Dental and oral health is of vital importance because of its effects on chewing, swallowing and speech and essential to avoid the increased risk of caries, gingivitis and periodontitis that comes with dental and oral care neglect (Kidd, 2005; Klinge & Gustavsson, 2011). Individuals with HD often need to increase the number of daily meals and the energy content in their food, they have decreased flow of saliva and frequently also anti depressant medication which create dry mouth. These factors all contribute to a danger of oral and dental health problems.

In dealing with dental and oral health care, significant others play an important role. Problems with fine motor control makes it more difficult for the person with HD to manage toothbrush, dental floss, fluoride tablets etc. and the cognitive problems are challenging when trying to follow instructions and remembering the appropriate use of different items (Gabre, 2009). The visit to the dental hygienist is not unique in this sense. Murphy (2006) investigated communication between health care personnel and persons with aphasia or cognitive disabilities. Both patients and personnel experienced misunderstandings because of communication difficulties. The patients had problems remembering what they wanted to say and following instructions from the doctor. Doctors also used words that the patients didn't understand. The patients expressed the need to have information given in writing and with supporting pictures. All social activities are related to certain procedures, goals and roles that influence communication in different ways. As far as the support of persons with cognitive and communicative disabilities is concerned, it is important to take these activity factors into consideration (cf. Ahlsén, 1995; Allwood, 2000).

Talking Mats™, TM (Murphy & Cameron, 2006) is a method used to enable persons with cognitive and communicative difficulties to express their opinions (see Figure 1). Talking Mats does not replace a person's communication aid but can be used without or together

with a communication aid. The method consists of a textured mat on which relevant pictures are stuck in a structured way. There are three sets of pictures: a visual evaluation scale, a picture describing a topic and pictures associated with the different questions relating to the topic. The conversation partner (the person responsible for the TM conversation, e.g. a nurse, a speech-language pathologist, or as in this case, a dental hygienist) formulates open questions such as: "How does it work to use...?", "What to you think of...?" etc. In addition to the prepared picture-based questions, new issues written down on pieces of note paper or empty cards can also be added. The person answering the questions (the person with difficulties expressing themselves, in this case individuals with HD) places the picture representing a specific question below the picture in the visual evaluation scale that best matches his or her opinion, but can also point to the part of the evaluation scale where the picture should be put. At the end of the conversation, the conversation partner recapitulates the discussion and seeks confirmation regarding the opinions expressed by the person being interviewed (Murphy & Cameron, 2006).

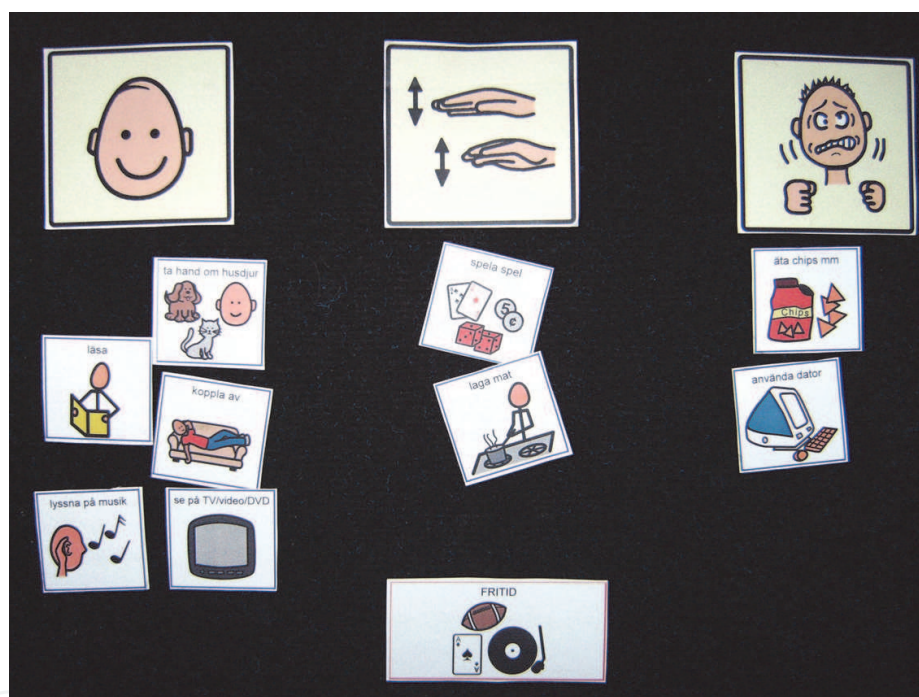


Fig. 1. A mat (Talking Mats) including a visual evaluation scale at the top, a picture for the conversational topic at the bottom, and pictures for different questions relating to the topic in the middle. The figure includes Picture Communication Symbols © 1981-2011 by Mayer-Johnson LLC.

One aim of conversations using TM is increased communicative involvement. Murphy et al. (2010b) conducted a study where individuals with dementia and their significant partners were engaged in two types of conversation, with and without TM. The conversations were on everyday topics such as personal care and household work. Results showed that persons with dementia as well as their partners felt significantly more involved in the conversations using TM and the increase was significantly higher for the partners compared to the participants with dementia. Communication effectiveness was assessed to be significantly higher in the conversation using TM compared to without TM.

Ferm et al. (2010) compared unstructured and structured conversations with conversations using TM with five individuals in different stages of HD. Conversations were compared with respect to communication effectiveness as measured by EFFC (Effectiveness Framework for Functional Communication, Murphy & Cameron, 2008). Communication effectiveness was significantly higher in the structured conversation as compared to the unstructured and highest in the conversation using TM. The conversation partner expressed the view that the persons with HD showed a greater involvement in the conversation and also that it felt more natural to wait quietly for the participant's answer when using TM. Talking Mats as a communication support has also been tried successfully in group discussions for persons with HD (Hallberg et al., 2011) but not yet in real health care situations. The participants in the discussion group studied by Hallberg et al. were more effective communicating about diet and health when TM was used than when the questions around these topics were discussed without TM. The difference in communicative effectiveness between the conditions was significant on both individual and group levels. Another interesting finding of this study was that the group leader and some of the individuals with HD asked significantly more follow-up questions when using TM than when the group discussion was unaided. Over all the group members with HD were positive about using TM.

As mentioned earlier, one of the health care situations that persons with HD encounter is dental and oral care. In Gothenburg, Sweden, most individuals with HD visit the dental hygienist between once a month and once every third month, to create or to keep a good dental and oral health. During a typical visit, a good part of the communication is done when the patient receives his or her treatment, lying down in the dental chair. The dental hygienist starts by talking about general things to make the patient feel at ease and continues on to give instructions, frequently with the support of pictures. When the ability to care for their own dental and oral hygiene is decreased, the instructions are given to the person supporting the patient during the visit (e.g. family member, assistant or carer). Communicative support in the dental and oral health care situation is of great value (Lewis et al., 2008) and the development and evaluation of appropriate support methods is important.

The aim of the present study was to explore the use of Talking Mats in conversations with individuals with HD in the dental and oral health care situation. The specific research questions asked were: 1) is there a significant difference in communicative effectiveness between conversations where Talking Mats is used compared to conversations where TM is not used?, 2) Is there a significant difference in perceived communicative involvement between the two types of conversation on the part of the individuals with HD?, 3) Is there a difference in perceived communicative involvement between the two types of conversation on the part of the support persons? And 4) Does the dental hygienist perceive the use of TM as a beneficial support in the dental and oral health care consultation?

### 3. Method

The study was designed to compare two different types of conversations between persons with HD, their support persons and a dental hygienist using both quantitative and qualitative methodology. Data was collected during naturally occurring dental and oral health care consultations.



3.1 Participants

Twenty four persons participated in the study; eleven individuals with HD (seven men and four women, mean age = 52 years, range 24 – 75 years), twelve support persons and a dental hygienist. The same dental hygienist carried out all conversations. The individuals with HD and their partners formed eleven dyads. As can be seen in Table 1, dyad 1 included two assistants which meant it really was a triad (i.e., included three individuals). For the sake of simplicity, we will call it a dyad. The support persons were relatives and professionals that accompanied the person with HD to the dental hygienist. Ten of the participants with HD had continuous contact with the dental hygienist; one participant had met the dental hygienist a couple of times. The dental hygienist was trained in TM but had limited experience in its use.

Dyad	Participants	Age	Onset HD	Phase	Education	Used TM before	Length of relationship (years)
F1	F1	53	40	4	compulsory school	yes	10 months 1 year
	F1(A)ass	55			high school	no	
	F1(B)ass	28			high school	no	
F2	F2	75	57	5	university	yes	>50 yrs
	F2husband	77			university	no	
F3	F3	64	58	3-4	university	yes	3.5 yrs
	F3ass	59			university	no	
F4	F4	58	50	4-5	university	no	5 months
	F4ass	19			high school	no	
M1	M1	24	20	4	high school	yes	6 months
	M1ass	45			high school	no	
M2	M2	28	22	3	high school	yes	3.5 years
	M2ass	57			compulsory school	no	
M3	M3	57	47	4	university	no	3 years
	M3ass	22			high school	no	
M4	M4	46	30	3	university	yes	2.5 years
	M4ass	50			high school	no	
M5	M5	52	50	3	compulsory school	no	1.5 years
	M5support person	46			university	no	
M6	M6	57	52	no info	compulsory school	no	a couple of years
	M6counselor	43			university	no	
M7	M7	57	54-55	2	compulsory school	no	29 years
	M7daughter	29			high school	no	

Table 1. Participant characteristics. F = female; M = male; Onset HD = Age of first symptoms of HD, Phase = TFC-phase (Shoulson et al., 1989) for the participant with HD according to the dental hygienist, Education = highest completed education, ass = personal assistant; Length of relationship = number of months or years the participants had known each other.

Invitation of participants was done by the dental hygienist. All participants were registered as clients at Mun-H-Center<sup>1</sup>. Inclusion criteria were HD, contact with the dental hygienist and interest and willingness to participate in a study about communication support. No formal cognitive or linguistic assessments were made. However, persons in the late stage of the disease were not invited to participate. All participants communicated through speech and no one used personal communication aids during the visit at the dental hygienist's. The participants' speech varied in intelligibility.

### 3.2 Ethical considerations

The study built on relevant research and was led by professionals with expert knowledge within the fields of HD and augmentative and alternative communication. Participation was voluntary and built on informed consent. The individuals with HD and their support persons all signed consent forms. Due to the cognitive and linguistic difficulties accompanying HD particular attention was given to the process of informing the participants with HD. The study was described in detail by the dental hygienist and the researchers on three different occasions. Simplified written information with pictures was also supplied. The participants were informed that they could withdraw from the study at any time without specific reasons and without personal consequences. They were also informed that their data would be treated with integrity and that no names would be used in the dissemination of the results. All participants were informed about the results of the study and participants with HD received photographs of their mats.

### 3.3 Material

Black textured mats (37 x 58 cm), five pictures (6 x 6 cm) representing a visual evaluation scale, a picture (5 x 5 cm) for the conversational topic oral hygiene and prophylaxis, and pictures (5 x 5 cm) of the questions relating to the topic were used. Velcro on the back of the pictures allowed these to be placed and moved around on the mat. Digital photographs and Picture Communication Symbols PCS (Mayer-Johnson<sup>TM</sup>, 1981-2011) were used.

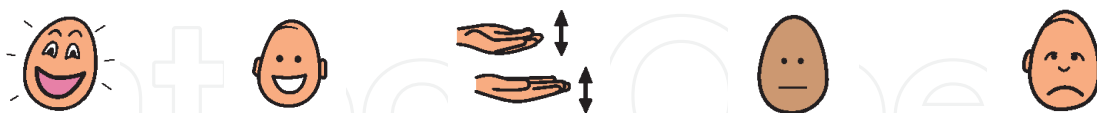


Fig. 2. The visual evaluation scale used with Talking Mats. The figure includes Picture Communication Symbols © 1981-2011 by Mayer Johnson LLC.

Twenty questions about oral hygiene and prophylaxis were developed by the dental hygienist and the researchers (Table 2). The questions formed two sets which included ten questions each. The questions were designed to be equivalent with regard to content and level of difficulty. Each dyad received both sets of questions; one set in the condition where TM was used and the other set in the condition where TM was not used. The order of the

<sup>1</sup>Swedish national oro-facial centre of expertise for rare disorders and national resource centre for oro-facial assistive devices, Gothenburg, Sweden.

question sets and conditions (TM and nonTM) were counter balanced (Table 3). The purpose of using two different but equal sets of questions in the two conditions was to create different but yet content wise similar conversations. In this way, the effects of TM, rather than of different questions, could be evaluated.

Question	Set 1	Set 2
1	How does teeth brushing work?	What would you say about getting help with teeth brushing?
2	How does it work brushing the inside of your teeth?	How does it work brushing exactly where you intend to?
3	How does it work using a regular toothbrush?	How does it work using a double toothbrush?
4	What would you say about getting help cleaning between your teeth?	How does it work cleaning in between your teeth?
5	How does it work using an interspace toothbrush?	How does it work using dental floss?
6	How does self cleaning work?	How does it work rinsing the mouth after the meal?
7	How does it work using toothpaste with extra fluoride?	How does it work rinsing the mouth with fluoride?
8	How does it work using fluoride chewing gum?	How does it work using fluoride tablets?
9	How does it work using gel against mouth dryness?	How does it work using spray against mouth dryness?
10	How does it work sitting in the chair?	How does it work lying in the chair?

Table 2. The two sets of questions used in the two conditions, TM and nonTM.

The participant with HD and the support person each filled out two questionnaires about the two different conditions. The questionnaire regarding the nonTM condition included seven questions (1 to 7 below). The questionnaire regarding the TM condition included the same seven questions (1 to 7 below) and one additional question (8). Questions 1 to 5 and 7 were similar to the questions used by Murphy et al. (2010b). Questions 6 and 8 were constructed for this study. The questions were: (1) Do you think that the questions asked were relevant for you? (2) Did the others listen to you in the conversation? (3) Were you able to express your opinions? (4) Did you have enough time to express your opinions? (5) Did you feel involved in the conversation? (6) Did it work well doing this together with NN? (7) How well do you think the conversation went? Circle the picture that best suits your opinion! (8) What do you think about using Talking Mats? Describe with your own words! A visual scale including four pictures of the concepts all/always, most/usually, a few/occasionally and none/never was used for questions 1 to 6. A seven point scale representing the continuum bad to excellent was used for question 7. The scales included pictures (Mayer-Johnsson™, 1981-2011) and were similar to the ones used by Murphy et al. (2010b).

The dental hygienist filled out two questionnaires for each dyad; one for the nonTM condition and one for the TM condition. The questionnaires included seven identical



questions: (1) To what degree did the person with HD understand the questions? (2) To what degree did you get carefully considered answers to the questions? (3) To what degree did you feel listened to in the conversation? (4) How natural was the conversation? (5) How easy was it to stay on topic in this conversation? (6) How involved did you feel in the conversation? (7) How well do you think the conversation went? Circle the picture that best suits your opinion! Questions 1 to 6 and 7 were answered according to the same four and seven point scales that were used by the participants with HD and by the support persons.

After each consultation, a semi-structured interview was carried out with the dental hygienist. The interview included six open questions about the two conditions and about TM.

The consultations, with and without TM, were recorded using a Canon HD Legria HF S11 camera and the mats were photographed using a Panasonic Lumix DMC-TZ8.

The Effectiveness Framework of Functional Communication EFFC (Murphy & Cameron, 2008) was used to measure communicative effectiveness in the two conditions.

3.4 Procedure

Data collection was done during regular consultations with the dental hygienist at Mun-H-Center (9 dyads), at one participant’s home (1 dyad), and at an activity centre (1 dyad) from November 2010 to February 2011. There were totally eleven consultations, one for each dyad. During each consultation two different conversations were carried out; one with Talking Mats (TM) and one without Talking Mats (nonTM). Consequently, there were 22 conversations in total. Each consultation started with repeated information about the study by the researchers and the signing of consent forms. A short conversation with TM was demonstrated. Thereafter the main researchers (second and third authors) left the room and the dental hygienist carried out the TM and nonTM conditions with the dyad. The dental hygienist was informed about the order of conditions and question sets for each dyad (Table 3) and about the fact that additional questions were allowed. The ten questions within each set were asked in the same order. Both conversations were recorded with a digital video camera. Towards the end of each session, some of the participants received dental treatment by the hygienist.

Dyad	Condition	Question set
M1, F2, M6	TM	1
	nonTM	2
M2, M4, M7	nonTM	2
	TM	1
M3, F3, F4	TM	2
	nonTM	1
F1, M5	nonTM	1
	TM	2

Table 3. Order of conditions and question sets for the eleven dyads.

After the completion of the two conversations the participants filled out the questionnaires. One researcher assisted the persons with HD who needed it by reading the questions aloud and by noting which picture in the visual scale the person pointed to. For question 8, the persons with HD were encouraged to describe their opinions about TM. These were written down by the researcher. The support persons filled out the questionnaires independently but a researcher was close by in case any of them had questions. The two questionnaires were answered in the same order as the two conditions had been carried out. The dental hygienist filled out the questionnaire on her own after the completion of the two conversations. The interview was carried out at the end of the consultation, that is, after the dental treatment. One researcher asked the questions and the other researcher took notes.

Data was compiled and communicative effectiveness as well as the participants' feelings of communicative involvement and satisfaction in the two conditions were examined and compared on group and individual levels.

### 3.5 Analysis

The communicative effectiveness of the persons with HD in the two conditions was evaluated by the two researchers who also assisted with data collection during the consultations. The evaluation was done using EFFC (Murphy & Cameron, 2008). Each conversation was evaluated according to four factors namely (a) the participant's understanding of the questions, (b) the participant's engagement in the conversation, (c) the participant's ability to keep to the questions discussed, and (d) the interviewer's (dental hygienist) understanding of the participant's views. The evaluations were based on the criteria set out by Murphy et al. (2010b), Murphy et al. (2010a) and Ferm et al. (2010) but also depended on thorough discussions taking place between all the researchers in this particular study. Each conversation was evaluated according to the four factors and using a 5-point scale representing low (0) to high (4) effectiveness. The evaluation of the *participant's understanding of the questions* was based on both verbal answers and body communication. To get a high score it should be obvious that the person with HD understood the questions. Lack of answers, irrelevant or inadequate answers resulted in low scores as did misunderstandings. A lower score was also given if it was difficult to understand the person's answers and hence to make the evaluation. The *participant's engagement in the conversation* concerned the social closeness that is a result of social interaction and which is maintained through different kinds of feedback and shared attention. Facial gestures and other body communication as well as verbal feedback were observed. High scores depended on active engagement and interest shown through eye contact, explicit feedback, and humour or by the participant's development of a topic. It was decided that to get one or more points, more than a short answer was needed. The *participant's ability to keep to the questions discussed* was based on the relevance of the participant's answers and on his or her ability to stay on track when answering and discussing the questions. A lower score was given if the participant changed or drifted away from the topic and if it, considering the person's communicative contributions, was difficult to make an evaluation of the factor. The *interviewer's understanding of the participant's views* was evaluated on the basis of the dental hygienist's reactions, verbal and through body communication, to the participant's answers.

The two researchers were trained in EFFC by evaluating video-recordings of conversations involving persons with HD that were not used in the study. Thereafter, the films of the 22 conversations were evaluated in a randomized order. First, the two researchers rated each recording independently. This meant that they looked at the recording together but did their own rating. Subsequently, the researchers discussed their ratings and reached a consensus score for each factor in each recording. The maximum score for each conversation was 16. Twelve points is the cut-off for an acceptable level of effectiveness (Murphy et al., 2010a). To check for interrater reliability, two independent external raters evaluated 30 % of the data using the same procedure. To check for intra-rater reliability, the two main researchers did a second evaluation of 30 % of the data a week after the first evaluation. The two conditions were also compared with respect to time and with respect to number of questions and follow-up questions that were asked.

The answers to the questionnaire items were transferred to a descriptive scale as follows: all/always (4), most/usually (3), a few/occasionally (2), and none/never (1). The individual scores for the six questions were added to form a total involvement score for each condition and participant. Means were calculated as well. Written comments in questionnaires were analysed and categorised with regard to content.

Statistical calculations were done using SPSS (version 19). Internal interrater reliability, measured using intra-class correlation (ICC) was 0.85. External interrater reliability, between the main two researchers and the external raters, was 0.64. The reliability between the researchers was higher (0.91) for the nonTM condition than for the TM condition (0.78). Intrarater reliability calculated on the basis of the researchers' consensus scores was 0.96. Differences in scores of communicative effectiveness and involvement as well as differences in the duration of the two conditions were analysed using Wilcoxon Signed Ranks Test ( $p < 0.05$ ).

#### 4. Results

The inherent differences between the two types of conversations, with and without TM, had a few consequences that need to be kept in mind when interpreting the results. In the conversations using TM, the questions were introduced visibly using pictures presented to the participant. Also, in these conversations the participants had an opportunity to delete or add questions, while this was not an option in the conversation without TM. Several of the participants, particularly support persons, deleted as well as added questions both before the conversation started and during the conversations. Support persons were also more active in giving support during conversations using TM. After the TM conversations, the dental hygienist went through the answers together with the participants, who had an opportunity to change the answers. Some of the participants with HD chose to do so. In the conversations without TM, the questions were put to the participants with HD in the predetermined order, and the answers were not documented/written down, albeit recorded.

In the following, results will be presented according to the research questions being asked.

**4.1 Is there a significant difference in communicative effectiveness between conversations where Talking Mats is used compared to conversations where TM is not used?**

No statistically significant difference between the two types of conversation was found in this group (see Figure 3). Mean effectiveness score without TM (nonTM) was 12.27 (SD 3,26) and mean effectiveness score with TM was 11.45 (SD 2.98).

Individual ratings on the four different parameters of EFFC, together with the total score, are shown in Table 4. Six of the 11 participants with HD, were rated as more effective in their communication in conversations without TM and 3 were rated as equally effective in both conditions. Two individuals communicated more effectively using TM.

Additional qualitatively important aspects of communicative effectiveness are time (duration of the conversations) and number of questions and follow-up questions being asked. Table 5 shows that conversations where TM were used were significantly longer than conversations without TM. This is in part due to the fact that the TM conversations included significantly more follow-up questions, see Table 6.

Research questions number 2 and 3 concerned the perceived communicative involvement on the part of the individuals with HD and the support persons. These questions were answered using the previously described questionnaires.

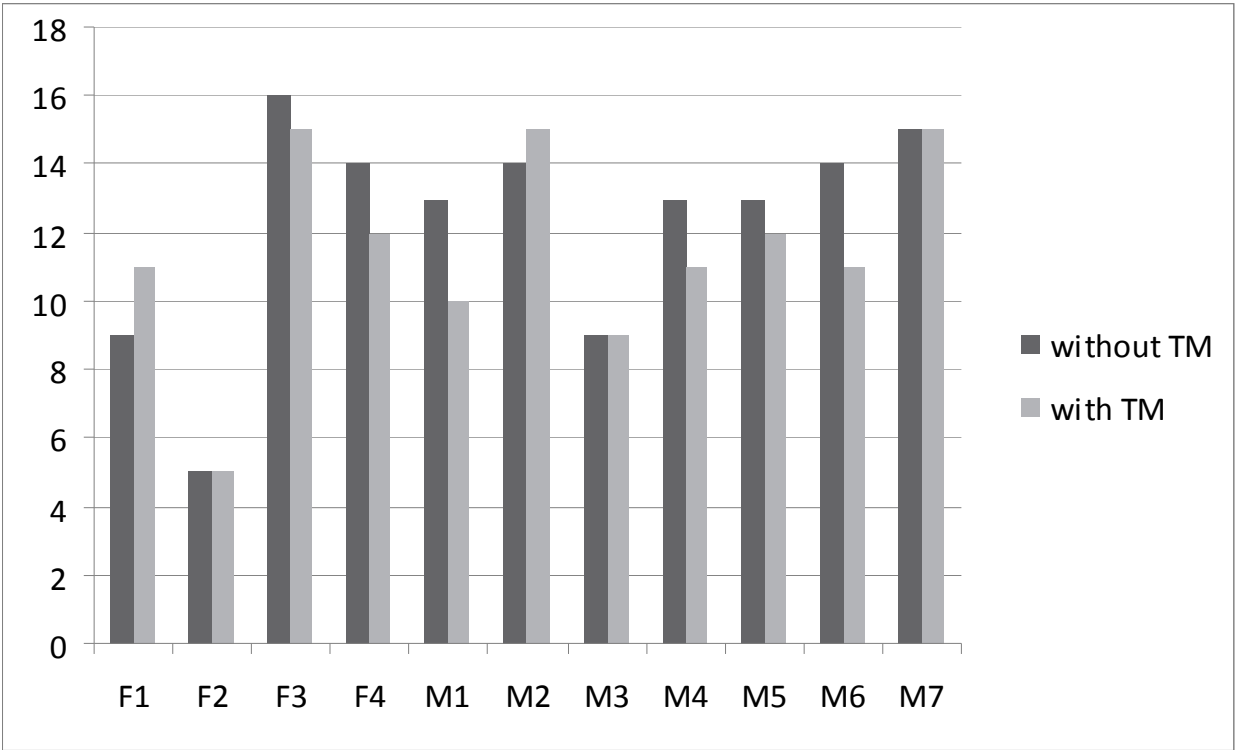


Fig. 3. Communicative effectiveness, as measured by EFFC, in conversations with (grey bars) and without Talking Mats (black bars). Acceptable communicative effectiveness cut-off value is 12 points.

Participant	Condition	Understanding	Engagement	Stick to the topic/questions	Interviewer's understanding	Effectiveness score
F1	nonTM	2	2	2	3	9
	TM	3	2	2	4	11
F2	TM	1	1	1	2	5
	nonTM	1	1	1	2	5
F3	TM	4	3	4	4	15
	nonTM	4	4	4	4	16
F4	TM	3	2	3	4	12
	nonTM	4	2	4	4	14
M1	TM	3	1	3	3	10
	nonTM	3	2	4	4	13
M2	nonTM	4	2	4	4	14
	TM	4	3	4	4	15
M3	TM	2	2	2	3	9
	nonTM	2	2	2	3	9
M4	nonTM	3	3	3	4	13
	TM	2	3	3	3	11
M5	nonTM	3	2	4	4	13
	TM	3	2	3	4	12
M6	TM	2	2	3	4	11
	nonTM	3	3	4	4	14
M7	nonTM	4	3	4	4	15
	TM	4	3	4	4	15

Table 4. Individual ratings and effectiveness scores of the eleven participants with HD. N.B.: nonTM = without Talking Mats, TM = with Talking Mats.

	nonTM	TM
Mean (SD)	3.7 (0.89)	12.8 (4.01)
Max	5.78	19.38
Min	2.47	7.68

Table 5. Duration of conversations in minutes, without (nonTM) and with (TM) Talking Mats. The difference is statistically significant (Wilcoxon Signed Rank test, p= .003).

	nonTM		TM	
	Questions	Follow-up questions	Questions	Follow-up questions
Mean (SD)	9.82 (0.41)	3.55 (2.12)	10.09(0.83)	9.64 (4.23)
Max	10	7	11	15
Min	9	1	9	3

Table 6. Number of questions and follow-up questions being asked by the dental hygienist during the two different types of conversations, without (nonTM) and with (TM) Talking Mats. The difference is statistically significant (Wilcoxon Signed Rank test, p= .005).



**4.2 Is there a significant difference in perceived communicative involvement between the two types of conversation on the part of the individuals with HD? And is there a difference in perceived communicative involvement between the two types of conversation on the part of the support persons?**

The participants with HD rated their communicative involvement significantly higher in conversations using TM compared to conversations without TM (nonTM). Differences between the two conditions were not statistically significant for the support persons or the dental hygienist, see Table 7.

	Participants with HD		Support persons		Dental hygienist	
Conversation type	nonTM	TM	nonTM	TM	nonTM	TM
Mean(SD)	21 (2.37)	22.45 (1.51)	21.25 (3.05)	21.50 (2.58)	20.27 (2.61)	20.82 (2.14)
Max	24	24	24	24	23	24
Min	18	20	15	15	16	16

Table 7. Ratings of perceived communicative involvement during the two different types of conversations, without (nonTM) and with (TM) Talking Mats. The difference is statistically significant for the participants with HD (Wilcoxon Signed Rank test,  $p = .048$ ) but not for the support persons or the dental hygienist.

The participants’ reactions to the use of TM were also collected and a general finding was that participants with HD as well as support persons were positive. A qualitative analysis of the notes generated four themes: *Understanding*, *Thinking and memory*, *Expressive function* and *The use of Talking Mats*. Themes and associated quotes are included in Table 8.

Theme	Illustrative quotes from participants with HD	Illustrative quotes from support persons
Understanding	<i>"people who do not understand sometimes people do not understand, then it would be good"</i> (M3) <i>"easier if you find yourself in a conflict situation, which I avoid, then it would be good"</i> (M3)	<i>"you don't always understand what he says, in that case he can show and point out"</i> (assistant to M4) <i>"I think the pictures are good, they help with understanding and being able to express oneself"</i> (assistant to F1) <i>"She understood more with the pictures"</i> (assistant to F1)
Thinking and memory	<i>"it's easier to think and understand when there are pictures"</i> (M7) <i>"made me think some more about the different stuff with oral care, that can be good"</i> (M5)	<i>"he has a fairly poor memory, and then you can take out the mat and show what we agreed on"</i> (assistant to M4) <i>"it can be useful to remember what you talked about even if the verbal communication does work"</i> (assistant to F3) <i>"she has difficulties making decisions and form opinions"</i> (husband to F2)

Expressive function	<i>"you can express feelings just by pointing to a face" (M4)</i> <i>"it is a bit easier to find the words with the mat" (M2)</i> <i>"it is a bit easier to talk about it with the mat" (M2)</i>	<i>"it clarifies when the words get muddy" (assistant to M1)</i> <i>"he talked more with the help from the Talking Mats" (counselor M6)</i>
The use of Talking Mats	<i>"damn good with pictures" (M3)</i> <i>"I didn't think it was going to be so easy" (M3)</i> <i>"it became a bit slow with the mat and better flow in the conversation without the mat" (F4)</i>	<i>"it was easier than I thought, and I don't think she had any difficulties with it either" (assistant to F4)</i> <i>"to think about using it during the right phase of the illness. To not be offended" (support person to M5)</i> <i>"a good "tool" to use in the future should it be necessary" (daughter of M7)</i> <i>"the mat was very good used like that regularly it will be great" (assistant to M3)</i> <i>"maybe clearer instruction before the interview about the use of Talking Mats about the pictures that was graded and the questions/conversation topic words" (counselor to M6)</i> <i>"felt a bit conflicting at times – several things in one picture that were opposites" (assistant to F3)</i> <i>"it is a bit difficult to say, I didn't know if I could expand, I was afraid to take over too much, I wanted to add more questions but didn't really know how much I was allowed to ask" (assistant to M2)</i> <i>"I didn't really know how much I was supposed to interfere in the conversation" (assistant to K3)</i>

Table 8. Themes and quotes from the interviews with participants with HD and support persons, concerning the use of Talking Mats.

The last research question concerned the perceived benefit of the use of TM as reported by the dental hygienist in the interview conducted after the consultation had been completed and both types of conversations implemented.

4.3 Does the dental hygienist perceive the use of TM as a beneficial support in the dental and oral health care consultation?

In the interview, the dental hygienist expressed the general view that the use of TM supported the counseling and treatment of persons with HD. Her opinion was, that all conversations using TM were superior to the conversations without TM. The qualitative analysis of her answers to the interview questions yielded six different themes: *Talking Mats as a method, Information and intervention, Individual adjustments, Memory, Understanding, and Naturalness.*

*Talking Mats as a method.* TM made the conversation obvious, transparent and concrete. One particular advantage of the method was that you were able to review the answers afterwards: *"the possibility to go back, add and comment on things in the conversation"*. The use of TM also gave a visible overview of the conversation. The pictures served as support for the memory both for the dental hygienist and the patient and they made the conversation concrete: *"easier to talk and discuss with the pictures as a support"*. The method Talking Mats and the mat in itself created a joint focus for the participants *"you have the whole conversation in front of you, it's there on the table"*. At times, the dental hygienist found it difficult to stick to the preset wordings of the questions: *"the questions are a bit tricky sometimes"*. It was evident from her answers to the questionnaire, that she found it difficult to engage in the conversations without TM – *"it feels as though you only want to get it over with"*, particularly if it was the second conversation: *"I don't feel as engaged when I'm going to ask almost the same questions again"*.

*Information and intervention.* One other positive aspect of the use of TM in conversation was that new and more in-depth information about several of the participants' oral and dental care appeared: *"I found out that she has difficulties remembering to brush her teeth but that she wants to be reminded"*, *"you can go deeper into the questions"*. Three participants with HD wanted to try new products or methods when they communicated using TM: *"it became apparent that the patient was interested in cleaning between his teeth, I thought this was impossible before, he has a strong sense of integrity"*. The dental hygienist experienced that two support persons contributed with new thoughts in the TM conversation: *"new thoughts appeared from the assistants"*.

*Individual adjustments.* The dental hygienist described that she would have wanted the opportunity to adjust the questions to particular individuals. In the present study, for the sake of consistency, she had to ask questions that were not relevant to all participants with HD: *"you have to individualize the picture material so that you can adjust the questions/pictures to the patients"*, *"I know that patient so it feels a bit silly to ask about things that are not relevant for that person"*.

*Memory, Understanding and Naturalness.* The dental hygienist saw TM as a support for her own memory: *"it supports the memory, you remember what the conversation has been about, what you have talked about"*, *"good when you go through the answers afterwards you remember what you talked about"*. Talking Mats seemed to make things more visible and clear both for her and for the participant with HD: *"easier for me to understand and probably also for the patient"*, *"it's good because it's difficult to understand what he says, you have to ask again, and in that case the mat helps"*. In two conversations using TM, with F4 and M7, the dental hygienist experienced that TM affected naturalness: *"it felt a bit repetitive, it did not have the same flow as earlier conversations using TM"*, *"it (the TM conversation) is not an ordinary conversation"*.

## 5. Discussion

We examined communicative effectiveness in conversations between persons with HD, their support persons and a dental hygienist, with and without Talking Mats. We also examined the participants' experiences from the two conditions as well as the dental hygienist's

experiences from using TM in dental and oral health care consultations. To summarise, there was no increase in communicative effectiveness for the group when TM was used. Two individuals communicated more effectively with TM but more than half of the participants were evaluated as more effective when TM was not used. Three individuals were evaluated as equally effective in the two conditions. Importantly, the participants with HD experienced a significantly higher degree of communicative involvement when TM was used than when conversation was unaided. The support persons also experienced a higher degree of communicative involvement with TM than without TM but this difference between conditions was not significant. The dental hygienist was very positive about TM. In her view, conversations with TM worked better than those without TM. She received new and more comprehensive information when TM was used.

Previous studies have shown that TM leads to more effective communication for persons with dementia and for persons with HD in dyadic as well as group conversations (Ferm et al., 2010; Hallberg et al., 2011; Murphy et al., 2010a, 2010b). A number of differences between this and previous studies regarding the way data was collected, goals, roles and procedures of activities may have contributed to the different results obtained.

Individuals with HD have many medical and health related contacts in which communication is of central importance. A purpose of the present study was to examine if TM could be helpful in such consultations. Thus, it was important to collect data in situations that were as natural as possible. It was believed that it was more natural if all data from each participant was collected during one and the same consultation than if the participant had to come back to the dental hygienist a second time, just to finish data collection. Hence, all data from each participant was collected on one occasion. This procedure is different from that of previous TM studies of effectiveness and could have influenced the participants' behaviours and the rating of effectiveness. For example, it may have been unnatural as well as tiring for the participants to answer similar questions twice during one and the same visit. However, four of the six participants that were scored as more effective without the mat carried out this condition after they had used the mat. Perhaps it was even positive for these individuals, with varying levels of cognitive functioning, to hear the questions twice. The fact that the participants had answered questions before may have contributed to less hesitation and more concise answers. It is possible that these answers were seen as efficient and informative and thus rated as more effective by the outside observers.

Another important difference between this and previous studies is that previous studies examined activities where communication was a main goal. It has also been the case in previous studies, at least in the study by Ferm et al. (2010), that the activity was constructed for the study. Although communication is important in dental and oral health care consultations it typically is not the main goal of the activity and although the present activity was natural for the participants and not constructed, it was slightly changed as far as procedure and goals are concerned. Communication usually takes place when the patient lies in the treatment chair and the goal is to promote good oral health; the patient gives information about his or her dental and oral status upon questions and requests from the dental hygienist who, based on the information given by the patient, gives advice about care routines, aids and products. In this study, the consultation started by the table. Communication about dental and oral health was "lifted out" from the more "practical"



dental treatment and in this sense got a different and somewhat more prominent function than the participants were used to. The change of the activity, and the fact that communication was more in focus than is often the case at the dental hygienist's, may have led to increased demands on the person with HD to, for example, give more nuanced answers than yes and no when TM was not used. Such changes in communication may have influenced the observers' ratings.

Dental hygienist consultations are typically associated with different roles which were slightly changed in this study. These changes, pertaining to the rights and obligations of support persons in particular (cf. Allwood, 2000), may have influenced the participants' communicative behaviours in ways that had effects on the ratings. The dental hygienist usually leads the activity and the patient, in this case the participant with HD, is supposed to do what the dental hygienist suggests. The support person usually does not accompany the person with HD into the treatment room but a prerequisite for participation in this study was that both the person with HD and a partner participated in the consultation. It is possible that the role of the partner was unclear. It was an unfamiliar situation for the partner both to discuss dental and oral health care and to participate actively in the conversation. Eight of the support persons were personal assistants whose role, apart from assisting the person they work for in relation to practical issues, involves promoting independence in that person. To argue against and even question the opinions of the person with HD during his or her "private" consultation was perhaps difficult. The analysis showed that overall, the support persons participated little in the conversations but the personal assistants interfered more often than others. The support person was supposed to have knowledge about the dental and oral health of the person with HD. This was not the case in all dyads. Some of the support persons managed everything that had to do with oral care in the person with HD; others didn't know anything about this daily issue. Not having the knowledge needed for participation in the study probably affected the support persons' behaviour and communication negatively. The dental hygienist's role was also changed. She would usually ask questions as she performed the actual treatment. In this study she talked with the patient before the treatment. She also used a communication method that was new to her.

All of the above mentioned factors could have influenced the participants' behaviours and, hence, the outside observers' rating of communicative effectiveness in the persons with HD. In future analyses, we will look more closely into these factors.

For two participants, F1 and M2, communicative effectiveness increased when TM was used. It is important to note that both of them had used TM before. For some people at least, communicative effectiveness with TM may be related to amount of experience as well. Both F1's own and the dental hygienist's understanding was higher in the TM condition. The TM conversation took a longer time which meant that F1's conversational space increased and, as a result, her and the dental hygienist's understanding. The dental hygienist asked F1 fewer clarifying questions (e.g., *And that works well?*) when TM was used which was interpreted as a sign for her better understanding. The situation was similar for M2. The TM conversation took a longer time and M2 had more room for developing his answers and showing humour, factors which, according to the criteria used, can have been a reason for why M2 was assessed as engaged in the TM conversation.



TM was assessed in three different ways; through outside observers' rating of communicative effectiveness, through the participants' responses to questionnaires about communicative involvement in the two conditions and through interviews with the dental hygienist. A most significant finding of the study is that the majority of the participants with HD and their support persons appreciated TM. Even if only two participants were more effective in conversations with TM, many participants appreciated the mat and thought it supported memory and word finding. Talking Mats also supported understanding in interaction. It was easier for the participants to make themselves understood and to understand others when TM was used. Interaction with other people is problematic for persons with HD who become less talkative and more isolated with the progression of the disease (Hartelius et al., 2010; Power et al., 2011). Finding ways to support participation in different social activities is important and the individual's ability to communicate in activities relating to own health should be prioritized. This study indicates that TM is one possible way of supporting communication between persons with HD and their conversational partners. The participants with HD felt significantly more involved, that is, experienced greater communicative involvement, when TM was used than when conversation was unaided. The support persons also experienced increased communicative involvement with TM but for them the difference between the two conditions was not significant. The support persons interfered more in the mat conversations. Some of them even assisted the person with HD, physically and psychologically, placing the pictures on the mat. Again, unclear instructions from the researchers and contradictions between the typical rights and obligations of assistants to promote independence in the person they work for and the expectations on assistants in this study, to converse with the person with HD on equal terms, may have contributed to the lack of significance between conditions as far as the support persons' feelings of communicative involvement is concerned. Still, the present findings are similar to those of Murphy et al. (2010b) where individuals with dementia and in particular their partners felt more involved in conversation when TM was used.

An all-embracing purpose of the study was to explore the use and function of TM for individuals with HD at the dental hygienist's and perhaps the most interesting finding is the fact that the dental hygienist experienced that TM conversations were better than conversations in which TM was not used. The dental hygienist also asked more follow-up questions when TM was used, indicating that TM stimulated conversation. A similar pattern was found in the study by Hallberg et al. (2011): In this study both the leader of the group discussions and the participants with HD asked more follow-up questions when they used TM than when they didn't have this support. By asking follow-up questions the dental hygienist could get more information about the dental and oral care situation of the person who has HD and as a result, she appreciated the situation. In her view, she got new and more comprehensive information from the dyads when TM was used, information that could lead to improved counselling and individual treatments of individuals who have HD. The dental hygienist's comment about individualizing questions and pictures is in line with the methodology of TM and would not be a problem in her future clinical work. For more comprehensive discussions in relation to follow-up questions and other queries that arise during conversations, she could use sub-mats (Murphy & Cameron, 2006).

Measuring communicative effectiveness is not easy and as has been shown in this study, ratings by outside observers must be complemented with measurements of the interlocutors own experiences. What then, is the difference between communicative involvement and communicative effectiveness? The questions about involvement used in this study were developed from Murphy et al. (2010b). It is possible that they reflect not only involvement but also effectiveness. Questions number 2, 3 and 4 in the questionnaire used in this study relate to communicative effectiveness; to be able to convey a message in an effective way and to be able to influence other people (Hustad, 1999). Question 4 focuses on time for expression of opinions. Perhaps the participants, in answering this question, considered both how much time they got from others and to what degree they were able to take their time in the conversations. In fact, it is reasonable to believe that the participants' rating of communicative involvement mirrored their perceptions of how effective they had been in the conversations.

### 5.1 Using the EFFC

Despite lots of training and discussion of criteria the researchers experienced difficulties using the EFFC in relation to these data. A re-analysis of consensus discussions, recordings and final scores shows that there were more disagreement between the raters in relation to the TM conversations than in relation to the unaided conversations, suggesting the former were more difficult to rate. Lack of experience in TM and EFFC as well as too vague criteria were obvious threats to agreement. The researchers' experiences and ideas about an ideal "effective" dental hygienist consultation also may have influenced their rating of the participants' communicative effectiveness. It also may have been the case, that the raters favoured oral expressions and treated these differently from body communication in their ratings. For example, the criteria used for rating of the participant's *understanding of the questions* and *ability to keep to the questions discussed* meant that higher points were given if the person was very explicit in her or his oral expression. It is possible that, unconsciously of course, a very short, adequate and concise utterance by a participant was valued higher and accordingly rated higher than a quiet placement of a picture on the mat. Some individuals with HD had less eye contact with their support persons and the dental hygienist when using TM. This seems to have influenced the observers rating of the participants' *engagement*.

### 5.2 Limitations

The conversations examined in this study were conducted by a dental hygienist who had limited experience in using TM. She was instructed about the order of question sets, conditions and individual questions but was free to formulate follow-up questions. Treatment integrity (Schlosser, 2003), that is, the degree to which the dental hygienist followed the procedure as planned, was considerable. Each participant received most of the questions and she was consequent in using the open question format. It is important to remember that this study was carried out in an authentic clinical situation and that time pressure and the dental hygienist's previous knowledge about the participants' dental and oral health may have influenced the conversations. Several of the participants had to catch transportation service at scheduled times which may have been stressful for both them and

the dental hygienist. The dental hygienist's enthusiasm over TM and participation in the study certainly constituted threats to validity but were difficult to control and did not lead to higher ratings of TM conversations. Rather, it is possible that her enthusiasm affected her communicative behaviours in ways which had negative effects on the rating of effectiveness in participants with HD. Her satisfaction and hope in TM as a resource in her future clinical work may have influenced her ability to behave equally in the two conditions and to overestimate the benefits of TM in the interview.

A limitation of the study which, considering the purpose of exploring communication support in real life also is its strength, relates to the fact that each participant's data was collected on one occasion.

### 5.3 Strengths and clinical implications

The strengths of the study outweigh its limitations by far. A considerable set of interaction data involving as many as eleven individuals in different phases of HD and their support persons has been examined. The investigation of interaction in a natural health care situation is in itself unique. The fact that the intervention focused on the situation of individuals with HD, for whom communication is often complicated and related to the many other difficulties that come with the disease, makes the study even more interesting.

Both quantitative and qualitative methods were used and the fact the participants' own experiences were taken into consideration strengthens the ecological validity of the study.

Talking Mats is used by speech language pathologists (SLP), teachers and others who know of its benefits. The present findings suggest that TM could function as a communication support not only in dental and oral health care but also in other clinical care situations that are important for individuals with HD and those who care for them, for example in conversations with the physician, the dietician, the physiotherapist, the occupational therapist and the psychologist. With training and careful instruction to all people involved, TM could lead to increased communicative effectiveness and a feeling of communicative involvement for the person with disability as well as for conversation partners. Considering the strategies and experiences of conversation partners to individuals with communication difficulties is important (cf. Saldert et al., 2010).

More studies focusing the communication of individuals with cognitive and communicative disability in naturally occurring activities are needed. The present researchers' future contributions to the field include more comprehensive interaction analyses of the present data (Ferm & Saldert, 2011) as well as evaluations of TM in interactions between persons that have Parkinson's Disease and their partners at home.

## 6. Conclusion

Interactions between individuals with HD, their support persons and a dental hygienist have been examined regarding communicative effectiveness and perceived communicative involvement with and without Talking Mats (Murphy & Cameron, 2006). According to outside observers, TM may not lead to more effective communication for persons with HD

during dental and oral health care consultations. However, a most significant finding is that the participants found it valuable using the mat. Both the participants with HD and their partners felt more involved in the TM condition than when conversation was unaided. For example, the participants commented that it was easier expressing feelings with the mat, that it was a good method for reflecting on oral health and that it was easier thinking and understanding with the mat than without it. Participants also reported that the pictures supported memory. The dental hygienist was positive as well. It was easier for her to understand the views of some of the participants when she used TM. For example, patients, who typically were inflexible as far as oral hygiene and prophylaxis is concerned, were more open minded and positive towards trying new methods and aids when discussing these issues with TM. According to the dental hygienist, TM has the potential to support communication in consultations involving persons with HD and their partners. Clinical activities in which TM could be useful include instruction and treatment planning, individual goal setting and follow up.

To date, few studies have investigated the use and value of augmentative and alternative communication for persons with HD and their partners in different activities. Research focusing communication support in care situations hardly exists. In this sense, and because it was conducted within an ordinary clinical practice, the findings of this study are important for the rehabilitation and treatment of individuals with HD and those who care for them.

## 7. Acknowledgment

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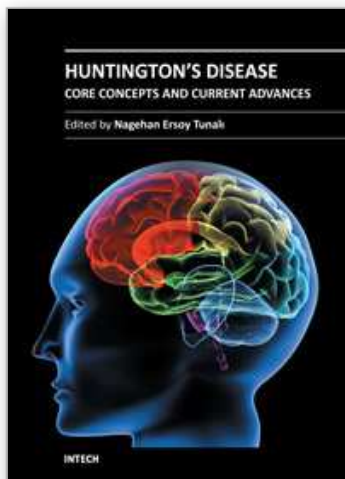


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## **Huntington's Disease - Core Concepts and Current Advances**

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Huntington's Disease is one of the well-studied neurodegenerative conditions, a quite devastating and currently incurable one. It is a brain disorder that causes certain types of neurons to become damaged, causing various parts of the brain to deteriorate and lose their function. This results in uncontrolled movements, loss of intellectual capabilities and behavioural disturbances. Since the identification of the causative mutation, there have been many significant developments in understanding the cellular and molecular perturbations. This book, "Huntington's Disease - Core Concepts and Current Advances", was prepared to serve as a source of up-to-date information on a wide range of issues involved in Huntington's Disease. It will help the clinicians, health care providers, researchers, graduate students and life science readers to increase their understanding of the clinical correlates, genetic aspects, neuropathological findings, cellular and molecular events and potential therapeutic interventions involved in HD. The book not only serves reviewed fundamental information on the disease but also presents original research in several disciplines, which collectively provide comprehensive description of the key issues in the area.

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